

**Project Name:** Screening Information System (SIS) Expanded Newborn and Prenatal Screening

**OCIO Project #:** Exempt

**Department:** California Department of Public Health (CDPH)

**Revision Date:** 9/13/10

## Concept Statement

### Description

#### Brief description of the proposed project:

Funding Source: Special fund (fund #0203) 100%

Center: Center for Family Health (CFH)

Start Date: 07/01/11

End Date: 06/30/15

Is BCP Needed: Yes (FY 11/12)

CDPH 2008-2010 Strategic Plan Goals: 1, 3, 4, 5

CA IT Strategic Plan Concepts and Strategies: 1(2), 2(3), 3(1,2,3,4), 4(1,2,3,4,5), 5(2,3), 6(1,2,3)

AIMS: 1(3), 2(3), 4(1,2)

Project Description: The Genetic Disease Screening Program (GDSP) manages two statewide screening (Newborn Screening [NBS] and Prenatal Screening [PNS]) programs that set the standard in the delivery of high quality, cost-effective genetic services to the constituents of California and make up the largest screening program in the world. Enhancements to the NBS program via legislative mandates are anticipated within the next five years. Since the legislation has not been enacted, solution alternatives have not been discussed. It is anticipated that solutions will include expansion of the current Screening Information System (SIS) application.

### Need Statement

#### High Level Capabilities Needed:

To support NBS & PNS programs, CDPH implemented a SIS application statewide in July 2005. Since then, new legislation passed which required an expansion of both programs and the SIS application in Jul+C55y of 2007. A major expansion of PNS and additional revisions to the SIS application were completed in January 2009. It is anticipated that the American College of Medical Genetics will (within the next 5 years) add Severe Combine Immunodeficiency Disease (SCID) and Lysosomal Storage Diseases (LSDs) for the NBS program. These changes will require additional revisions to the current application.

IT Projects will meet the requirements for accessibility for disabled persons as stipulated in the IT Policy Letter (ITPL) 10-10; State Management Manual (SAM) Sections 4819.2 and 4833; and State Administrative Manual (SAM) Sections 20, 25, 30.

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### What is Driving This Need?

The objective is to provide enhancement, maintenance and operational support of SIS in follow-up to the original SIS implementation project as legislative mandates require.

### Risk to the Organization if This Work is Not Done:

If CDPH does not implement the proposed project, daily operations of SIS and the clinical and billing functions it supports could be put at risk. SIS will cease to provide the additional mandated services.

## Benefit Statement

### Intangible Benefits

#### Process Improvements (describe the nature of the process improvement):

The system was designed to allow tests for additional disorders to be added when needed and has resulted in an increase in the number of disorders that have been detected and treated from 39 to 76. This project will add screening for two additional genetic disorders. This built-in efficiency is consistent with CDPH's mission to optimize the health and well-being of the people of California by providing or ensuring access to quality, population-based health services.

#### Other Intangible Benefits:

Mothers, babies as well as the entire genetic disease screening community will benefit from the additional data captured and managed in SIS. SIS enables CDPH to intervene at an early stage to significantly increase the likelihood that the chances of a baby born with a genetic abnormality can be saved from suffering mental retardation, other handicapping conditions or premature death. As a result, Californians can look forward to receiving more extensive information regarding a wider set of disorders that will help children lead healthy lives. GDSP will align with CA IT Strategic Plan such as Fulfilling Technology's Potential to Transform Lives, Self-Governance in the digital Age, Information as an Asset, Economic and Sustainable and Facilitating Collaboration that Breeds Better Solutions. As well as meet the following CDPH IT Strategic Goals: Increase Quality and Years of Healthy Life, Reduce Disparities and Promote Health Equity and Improve Quality and Availability of Data to Inform Public Health Decision Making.

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### Tangible Benefits

**Revenue Generation** (describe how revenue will be generated):

N/A

**Cost Savings** (describe how cost will be reduced):

N/A

**Cost Avoidance** (describe the cost and how avoided):

N/A

**Risk Avoidance** (describe the risk and how avoided):

NA

**Improved Services:**

N/A

## CA - PMM

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### Consistency

"No" Responses 		Rationale	Action Required
Enterprise Architecture	Yes		
Business Plan	Yes		
Strategic Plan	Yes		

### Impact to Other Agencies

#### Nature of Impact to Other Agencies

**Agency:**

*Describe the nature of the impact:*

N/A

**Agency:**

*Describe the nature of the impact:*

N/A

**Agency:**

*Describe the nature of the impact:*

N/A

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*Describe the nature of the impact:*

N/A

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### Solution Alternatives

#### Alternative 1:

Alternative Description: Since the legislation has not been enacted, solution alternatives have not been discussed. It is anticipated that solutions will include expansion of the current Screening Information System (SIS) application. Complying with legislative mandates requires implementing screening according to recommendations within one year of receipt of the recommendations of American College of Medical Genetics (ACMG) or other DHS-approved entity and unless DPH determines the screening is not necessary for advancing newborn health, and notifies the appropriate committees of jurisdiction in the Legislature of this determination. Screening for conditions recommended by the ACMG are unique and therefore their implementation scope varies. To meet these mandates in a timely manner we have in the past employed outsourcing. ROM costs for the solution are based on the last SIS Expansion project completed in January 2009.

#### Technical Considerations for Alternative 1:

**Hosting Location: (DHCS-ITSD)**

The proposed solution will probably leverage the current Screening Information System application but technical considerations will be largely unknown until legislation is enacted.

ROM Cost: \$6,250,000 to \$18,750,000

**Note: high end of range must not exceed 200% of low end of range**

#### Alternative 2:

Other Alternatives will be discussed during the Feasibility Study and documented in the Feasibility Study Report (FSR).

#### Technical Considerations for Alternative 2:

Technical considerations for other Alternatives will be discussed during the Feasibility Study and documented in the FSR.

ROM Cost: to

**Note: high end of range must not exceed 200% of low end of range**

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	Alternative 3:
N/A	

Technical Considerations for Alternative 3:	
N/A	
ROM Cost:	to <b>Note: high end of range must not exceed 200% of low end of range</b>

## Recommendation

### Comparison:

Alternative 1	ROM Cost			Risk
Develop solution as mandated	\$6,250,000	-	\$18,750,000	NA
Alternative 2	ROM Cost			Risk
	\$0	-	\$0	NA
Alternative 3	ROM Cost			Risk
	\$0	-	\$0	NA

### Conclusions:

1	Health and Safety Code Section 125055 (g) (4) exempts the SIS Newborn and Prenatal Screening project from the requirement to submit an FSR.
2	
3	
4	

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### Recommendation:

Since the legislation has not been enacted, solution alternatives have not been discussed. It is anticipated that solutions will include expansion of the current Screening Information System (SIS) application. As such, any future amendments to the bill would expand the purposes of the screening program and constitute an appropriation. This project supports CDPH 2008-2010 Strategic Plan Goals: 1, 3, 4, 5 ; CA IT Strategic Plan Concepts and Strategies: 1(2) , 2(3), 4(1,2,3,4,5), 5(2,3) and 6(1,2,3); and Agency Information Management Strategy Goals and Objectives: 1(3), 2(3), 4(1,2).

### Project Approach (if known)

<b>System Complexity:</b>			System Business Hours: (e.g., 24x7, 9am-5pm) :		
Architecture	<input type="checkbox"/> Mainframe	<input type="checkbox"/> Client Server	<input type="checkbox"/> Web Based	Num. of New Databases:	
Technology	<input type="checkbox"/> New	<input type="checkbox"/> New to Staff	<input type="checkbox"/> In-House Experience	Interfaces:	External
Implementation	<input type="checkbox"/> Central Site	<input type="checkbox"/> Phased Roll-out		Num. of Sites:	
M & O Support	<input type="checkbox"/> Contractor	<input type="checkbox"/> Data Center	<input type="checkbox"/> Project	<input type="checkbox"/> In House	
Procurement Approach: Although planning is still in progress, we anticipate the proposed project will be consistent with the organization's methods and standards.					Number of Procurements:
Open Procurement?		Delegated Procurement?			
Scope of Contract	<input type="checkbox"/> Development	<input type="checkbox"/> Implementation	<input type="checkbox"/> M & O	<input type="checkbox"/> Other:	
Anticipated Length of Contract:		Years /		extensions for	years